

## *The Immortal Life of Henrietta Lacks* by Rebecca Skloot

### Extra Credit

You can raise your grade up to 5% in one nine weeks by completing the following extra credit assignment:

Read *The Immortal Life of Henrietta Lacks* by Rebecca Skloot. After each chapter, answer EACH of the following questions using complete sentences on another sheet of paper. Be sure to number your answers and group them by chapter.

#### **Prologue: The Woman in the Photograph**

1. How does the author create an interest in learning more about the story of Henrietta Lacks?
2. How well does the author provide the reader with a sense of what this book is about?

#### **Deborah's Voice**

3. What is your impression of Deborah, given this brief excerpt? How does the author shape that impression?

#### **Chapter 1: The Exam (1951)**

4. What does this chapter suggest to you about Henrietta Lacks' ability to understand and make informed decisions about her treatment at the clinic?
5. How would you describe Henrietta's attitudes toward medical care?
6. What does the term "Jim Crow era" mean?

#### **Chapter 2: Clover (1920 –1942)**

7. What do you think of the description of Henrietta's childhood years in Clover?
8. What is your impression of Henrietta after reading this chapter?
9. What are your thoughts about the employment opportunities for black men at Sparrows Point?

#### **Chapter 3: Diagnosis and Treatment (1951)**

10. What is your impression of medical understanding and treatment of cervical cancer in 1951?
11. Do you believe that Dr. TeLinde's research was important and justified?
12. What are your thoughts on using radium to treat cancer, when it is also a cause of cancer?
13. Read the Operation Permit that Henrietta signed. Do you think it gave the hospital the right to take tissue from Henrietta for research purposes? Do you think Henrietta was able to understand what she was signing?

**Chapter 4: The Birth of HeLa (1951)**

14. What is your impression of Dr. Gey? What evidence of his dedication to his work is given in this chapter?
15. Why did Dr. Gey give samples of the HeLa cells to his colleagues?
16. What are your thoughts on the issue of sterile procedures in the lab, given the descriptions of the lab in this chapter?

**Chapter 5: “Blackness Be Spreadin All Inside” (1951)**

17. How well do you think Henrietta understood her illness? Her treatment?
18. Why was Henrietta surprised to learn that she could not have children? Do you think she was not told, that she didn’t understand what she had been told, or that she had forgotten?

**Chapter 6: “Lady’s on the Phone” (1999)**

19. Why did Dr. Pattillo ask Rebecca Skloot what she knew about African Americans and science before deciding to let her contact the Lacks family?
20. Why do you think Deborah’s attitude changed so much from the first phone call to the second?
21. Given the responses from Deborah and Day, are you surprised that Rebecca Skloot continued this project?
22. From what was related in this chapter, how well do you think the Lacks family understood what had been done with Henrietta’s cells?

**Chapter 7: The Death and Life of Cell Culture**

23. Would it be possible for a scientist to make claims like Alexis Carrel’s today and have them as widely accepted by other scientists, the media, and the public?
24. Why was the development of an “immortal” cell line like HeLa potentially so important to medical research?

**Chapter 8: “A Miserable Specimen” (1951)**

25. How did the elevated status of doctors in the 1950s affect the quality of the medical care they gave to their patients, both positively and negatively?
26. What is your impression of the medical care Henrietta received? Do you think it was less than what a white patient might have received?

**Chapter 9: Turner Station (1999)**

27. What is your impression of Turner Station and the people who live there?
28. Based on what you have read so far, why do you think people are unwilling to talk to the author?

**Chapter 10: The Other Side of the Tracks (1999)**

29. What do you think of Cootie's understanding of HeLa cells?
30. Why does the author mention the radio program that playing in the background when she was talking with Cootie?
31. What is your impression of Clover, given the description in this chapter?

**Chapter 11: "The Devil of Pain Itself" (1951)**

32. How well liked was Henrietta in the Sparrows Point community?
33. Given the descriptions in this and other chapters, how close was the Lacks family? How does their family compare to your own, or to others you know about?
34. What is your reaction to the medical decisions regarding blood transfusions and discontinuing cancer treatment for Henrietta Lacks?

**Chapter 12: The Storm (1951)**

35. Why was it a surprise for Dr. Gey's assistant to suddenly think of Henrietta as a person when she saw the chipped toenail polish? Do doctors and scientists tend to see patients as bodies or specimens rather than as people? What other examples of this can you see in this book? Should doctors and scientists do this? Why or why not?
36. How did the Lacks cousins interpret the sudden storm during Henrietta's funeral? Do you agree?

**Chapter 13: The HeLa Factory (1951—1953)**

37. The author notes that Tuskegee Institute, site of the first HeLa production factory, was also home to the notorious Tuskegee Syphilis Study. How are these two projects similar? How are they different?
38. Why is standardization of procedures considered so critical to scientific research? How can that standardization also limit the growth of research?
39. Did Microbiological Associates have the right to begin growing and selling HeLa cells, even though they had played no role in developing them?

**Chapter 14: Helen Lane (1953—1954)**

40. What do you think of journalists trying to find out Henrietta's name and contact her family for their stories?
41. Why did George Gey decline to identify Henrietta Lacks for journalists?
42. Should Gey and his colleagues have informed the Lacks family about the origins of HeLa? Why or why not?

**Chapter 15: "Too Young to Remember" (1951—1965)**

43. Do you get a sense of Deborah's ambivalence in her feelings about Galen? How did that play a role in her molestation?
44. Why was Ethel able to get away with treating the Lacks children as she did for so long?
45. What do you think is going to become of Joe, given the treatment he got as a small child?

**Chapter 16: “Spending Eternity in the Same Place” (1999)**

46. Why did Cliff bring Skloot to the family cemetery?
47. How does race continue to play a role in communities like Clover?
48. Why do the “white” and “colored” Lacks families have different beliefs about their interconnections?
49. How does the Lacks family history presented here compare to that of Thomas Jefferson and Sally Hemings?

**Chapter 17: Illegal, Immoral, and Deplorable (1954—1966)**

50. What were the justifications given for Southam’s failure to inform his subjects?
51. What do you think of those justifications?
52. What is your reaction to Southam’s comment (p.134) on why he did not inject himself?

**Chapter 18: “Strangest Hybrid” (1960—1966)**

53. Why were scientists worried that cell and tissue research was becoming a disaster? What seemed to be going wrong?
54. Why did the Cell Culture Committee want to create a reference collection of cells? Why was it so important that these cells came directly from the original source?
55. Why were scientists working to fuse animal and human cells?
56. Do you approve or not approve of the idea of scientists creating human---animal hybrids for research? Why?

**Chapter 19: “The Most Critical Time on This Earth Is Now” (1966--1973)**

57. What was Joe trying to say when he wrote “the most critical time is now”?
58. How does Deborah’s relationship with Cheetah compare to Henrietta’s marriage to Day, described in Chapters 2 and 5? How are they similar and how are they different?
59. What shocking news do you think Deborah is about to get, and how well do you think she will handle it?

**Chapter 20: The HeLa Bomb (1966)**

60. What was the theory of spontaneous transformation? What significance did Gartler’s findings have for this theory?
61. Why was this report referred to as the “HeLa Bomb”?
62. Why will the effort to develop markers for HeLa contamination require contacting the Lacks family?

### **Chapter 21: Night Doctors (2000)**

63. Why did the family treat Rebecca Skloot differently from journalists who had come around before? What made her different?
64. What was the original intent of Johns Hopkins in setting up the hospital? Did the doctors working at the hospital live up to that intent?
65. What were the night doctors, and what impact did their activities have on American society?
66. Why do you think the Lacks family were not notified of what was being done with HeLa cells?
67. Suppose Henrietta Lacks had been your mother or grandmother. Would you be as upset as the Lacks family members? Why or why not?
68. Why were the Lacks family members so angry at the end of this chapter?
69. Do you think the Lacks family should have received some sort of compensation for the development and use of HeLa cells? After reading this chapter, what do you think should be done about their claims?

### **Chapter 22: “The Fame She So Richly Deserves” (1970 --1973)**

70. Would you volunteer to serve as a subject in medical research, as George Gey did? Why or why not?
71. What is the difference between epidermoid carcinoma and adenocarcinoma? Would a correct diagnosis have changed the way Henrietta Lacks was treated? Why was HeLa contamination a problem for research seeking a cancer virus?
72. Why was the finding that HeLa cells had contaminated Russian cancer cell research considered so newsworthy?

### **Chapter 23: “It’s Alive” (1973—1974)**

73. How could McKusick and his investigators have explained what they were doing in a way that made sense to the Lacks family?
74. Do you think McKusick and his colleagues were concerned about making certain the Lacks family understood what they were doing?
75. Do you think the investigators treated the Lacks family ethically? If not, do you think it was intentional or a misunderstanding?
76. What would you have done differently if you were Dr. McKusik? If you were Susan Hsu?
77. How would you feel if you discovered that investigators had taken cells or tissues from some member of your family without consent?
78. How are ethical standards for research on humans today treated differently than they were in the 1970s?
79. Do you think that an ethical standards review board could or should have anticipated the problems in communications between the Lacks family and the investigators?
80. Do you think the investigators feel today that they did anything wrong back then?

#### **Chapter 24: “Least They Can Do” (1975)**

81. Do you think that Johns Hopkins should be penalized or required to reimburse the Lacks family for using Henrietta Lacks’ tissue samples to develop and distribute HeLa?
82. Do you think the Lacks family would be justified in seeking payment from the various companies that had sold HeLa cells?
83. The *Science* article by McKusick and Hsu, published in 1976, provided identifying genetic information about members of the Lacks family. Should that have been done? Why is this illegal today?
84. What are the interests and conflicts that you see between the Lacks family, Johns Hopkins, the biotech firms selling HeLa, and the general scientific community? Given what you have read so far, how would you resolve those conflicts?

#### **Chapter 25: “Who Told You You Could Sell My Spleen?” (1976—1988)**

85. What is the author’s position on the issue of ownership of tissues used in medical research? What evidence did you use to make that judgment?
86. What is your own position on this issue? How do you feel about the decisions by the Court of Appeals and the California Supreme Court?
87. Should individuals receive financial compensation if their tissues are employed to develop a biological product, or should that go to the person who developed the product?
88. If your blood had been used to create a new vaccine, would you be satisfied knowing that others would benefit from your contribution, or would you feel that you should be financially rewarded? How much do you think you should get, and how much should the developers get?

#### **Chapter 26: Breach of Privacy (1981—1985)**

89. What impression of the Lacks family does Skloot create in this chapter?
90. Do you think that federal rules regarding patient confidentiality are necessary? Why?
91. Do you think Michael Gold should have published the information on Henrietta Lacks without receiving permission from her family? Did he make enough of an effort to contact them?

#### **Chapter 27: The Secret of Immortality (1984—1995)**

92. What role do telomeres play in determining how many times a cell can divide?
93. What is the Hayflick Limit?
94. Should research manipulating DNA be allowed? Why or why not?

#### **Chapter 28: After London (1996—1999)**

95. Were the consequences of increased recognition of Henrietta Lacks positive or negative for the Lacks family? Explain.
96. Why did Johns Hopkins respond to Barbara Wyche’s letter as it did?
97. How did Colfield manage to gain the trust of the Lacks family?
98. How did the attempt by Richard Kidwell, the Johns Hopkins attorney, to protect Deborah end up causing her breakdown?

### **Chapter 29: A Village of Henriettas (2000)**

99. Do you think you would have been as persistent at Rebecca Skloot in trying to make contact with Deborah Lacks?
100. What does Deborah mean when she says (p. 235), “I do want to go see them cells, but I’m not ready yet”?
101. When Rebecca reaches for the medical records Deborah snapped (p. 239), “We ain’t ready for that!” What does that response signify to you?

### **Chapter 30: Zakariyya (2000)**

102. Why does Zakariyya have so much difficulty with anger and aggression?
103. How would you feel if you were Rebecca, meeting Zakariyya for the first time?
104. Zakariyya commented, “Only people that can get any good from my mother cells is the people that got money, and whoever selling them cells – they get rich off our mother and we got nothing.” Do you think this statement is correct? What should the Lacks family get?

### **Chapter 31: HeLa, Goddess of Death (2000—2001)**

105. Look up more information about the Henrietta Lacks Foundation. How well has Rebecca done in carrying out her promise to Deborah?
106. Why did Rebecca send Deborah fictional accounts of HeLa as well as factual reports?
107. How would you feel if you discovered that your mother’s cells had been used in so many different research programs? How would your reactions be similar to Deborah’s? How would they differ?

### **Chapter 32: “All That’s My Mother” (2001)**

108. What are your thoughts about Lengauer’s suggestion that the Lacks family should get at least some of the money from the sale of HeLa cells?
109. Do you agree with the idea that it should be like oil royalties?
110. Zakariyya acted very differently when he left the lab. Why do you think that was?
111. How did the author use the statue of Jesus as a symbolic element in this chapter?

### **Chapter 33: The Hospital for the Negro Insane (2001)**

112. What was your reaction to the description of the conditions and studies being done at Crownsville back in the 1950s?
113. Paul Lurz said, “Sometimes learning can be just as painful as not knowing.” Do you think that was true for Deborah? Can you think of situations in your own life where this has been true?

### **Chapter 34: The Medical Records (2001)**

114. How do you think you would have handled that evening with Deborah, if you had been Rebecca?
115. What do you think was the underlying reason for Deborah’s volatility that evening?

### **Chapter 35: Soul Cleansing (2001)**

- 116. How did you react to the description of Gary's prayer that God relieve Deborah of her burden? How did Rebecca react?
- 117. Did the shift in Gary's behavior surprise you?
- 118. What is "catharsis"? Would you use that term to describe Deborah's reaction to Gary's prayers?

### **Chapter 36: Heavenly Bodies (2001)**

- 119. Do you think that Rebecca's own attitudes toward religion were changed by her experiences in working on this book?
- 120. Which explanation for the immortality of Henrietta's cells seems better, or more correct, to you? Why?

### **Chapter 37: "Nothing to Be Scared About" (2001)**

- 121. Why is this chapter titled "Nothing to be scared about"?
- 122. How can you explain Deborah's acceptance and calm determination after her stroke?

### **Chapter 38: The Long Road to Clover (2009)**

- 123. Why did Deborah come to such a different position regarding getting money for her mother's cells?
- 124. How much do you agree or disagree with each of the following?
  - a. Johns Hopkins should pay the Lacks for taking Henrietta Lacks' cells without
  - b. The companies that are selling HeLa cell lines should pay the Lacks family for the right to use those cells.
  - c. People should not be permitted to sell any body parts or tissues.
  - d. The Lacks family should be proud that the mother's cells have benefited so many people, but they are not entitled to any financial compensation.

### **Afterword**

- 125. What is the Common Rule regarding individual rights in research?
- 126. Do you agree with the assertion that people are morally obligated to allow tissues taken during medical and diagnostic procedures to be used for research that could potentially help others? What restrictions, if any, should people be allowed to place on research using their tissues?
- 127. Should companies that make money from information gained from individuals' cells or tissues be legally obligated to compensate those individuals? How would that compensation be determined?
- 128. Should individuals have the right to claim control over products developed from their own tissues or cells?